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Carer experiences of life after stroke – a qualitative analysis

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Abstract

Aims & objectives: Carers' experiences of caring for a stroke survivor were explored, including reactions and changes in their lives.

Method: A phenomenological approach was taken to the collection and analysis of data. Semi-structured interviews lasting an average of 43 minutes were carried out with nine informal carers in their own homes. All were married to someone who had survived a stroke.

Results: An overarching theme emerged, entitled: 'lives turned upside-down'. It took time for participants to understand the long-term impacts of stroke. Carers experienced increased caring and domestic workloads alongside reduced participation and altered expectations of life. They found emotional and cognitive changes in their partners particularly distressing, and would have valued more information and help with adjusting to the increased emotional, physical and cognitive workload of caring.

Conclusions: It is important to support carers of people who have survived a stroke in adjusting to their changed lifestyles. This may affect their quality of life as well as sustainability of caring, and requires further research.

Keywords: carer; stroke; functional electrical stimulation

Introduction

Stroke is a highly prevalent condition in both developed and developing countries. International mortality from stroke was estimated at 5.5 million in 2002, 9.6% of all deaths.[1] In the UK an estimated 150,000 people per year experience a stroke, making it the third highest cause of death. It is also a prominent cause of severe disability; 250,000 or more people in the UK live with its effects.[2] A large proportion are able to live at home, but require assistance from an informal carer to do so.[3] The unexpected nature of stroke and its frequently severe effects on life require major adjustments in carer's lives.[4]

Several systematic reviews have focused on the experiences of carers after stroke, most focusing on quantitative research.[5,6,7,8,9,10] Greater depression and psychological morbidity have been found in the carers of people with stroke than in the general population, [5,6] but a focus on psychological issues has been criticised due to neglect of physical, social and functional domains.[6] Greater depth of understanding can be gained through qualitative research, which explores experiences through individuals' own words. This is valuable, as the views and priorities of stroke survivors and carers do not always match the expectations of professionals.[11] Greater understanding of individuals' experiences of stroke may give insights into potential needs, as carers may not expect and request help for some of the difficulties that they experience.

Numerous qualitative studies have been conducted in relation to this topic; a recent systematic review located 17 studies published between 1996 and 2006 that related to experiences of caring for stroke survivors; while most studies achieved only moderate quality ratings there are similarities in the results.[12] Several described early reactions after the stroke occurred, including feelings of confusion and lack of

preparation for the caring role. There were difficulties in adjusting and coming to terms with dramatic lifestyle changes and greater uncertainty in life.[13,14,15,16] Frequent difficulties were described in relation to physical, social and emotional aspects of life. Caring was described by some as fatiguing and unrelenting,[14,17] and there were specific difficulties where carers had other health problems.[14] Many individuals were required to take on additional roles that were described in relation to greater stress; these included more of the household chores, financial and administrative tasks.[17,18,19,20] Role changes were further complicated where carers were responsible for other dependents as well as the stroke survivor.[14] This busier lifestyle was described in relation to greater social isolation, as opportunities for social contact were restricted;[16,17,20] one systematic review found that this increased over time.[12] Some carers worried about the future - their ability to continue caring; but otherwise tended to focus on thinking one day at a time.[14] Many had given up their own pleasures, with their own needs subordinated to those of their partners.[20] Individuals in studies often craved information, training and support to help them adjust and develop realistic expectations, to give greater confidence in the care they provided, and to enable access to services including respite.[13,14,20,21,22] However, the picture was not completely negative, as some studies identified satisfactions arising from caring, such as greater fulfilment and improved relationships.[12]

There is now a fairly extensive literature base relating to carers' experiences of stroke, although relatively few studies have been conducted in the UK, with only two identified in Scotland by a recent systematic review.[13] Furthermore, the process of gaining understanding of individuals' experience is ongoing, as health services continue to change over time and their impacts require exploration. Therefore this

article focuses on data from a larger study that related specifically to carers' descriptions and interpretations of their experiences of stroke.

Method

Study design

Experiences of stroke were explored as part of a larger study, conducted in 2007. This affected methodological choices – this background is important to enable the reader to judge transferability of findings. The original study was designed to explore the impact of a clinic for people who have dropped foot after stroke and potential to benefit from an electronic orthotic called Functional Electrical Stimulation (FES). This provides electrical stimulation to stimulate foot-lift during gait.[23] The main research question was: what are stroke survivor and carer experiences of stroke-related dropped foot and its management using FES? Rich data were also generated regarding the impacts of stroke on people's lives. This was felt to provide valuable retrospective insights into carers' experiences of life after stroke.

The study aimed to explore the lived experiences of individuals and describe them using a phenomenological qualitative perspective.[24] This approach aims to avoid making assumptions about how people interpret their experiences, while understanding that qualitative data collection, analysis, and interpretation are collaborative. Semi-structured interviews included questions about individuals' experiences of a stroke at the time of occurrence, and later.[25] Ethical approval was granted by the Local National Health Service Research Ethics Committee.

Sampling and recruitment

Participants were recruited via the local FES Clinic, with an approximate target of ten stroke survivors and ten carers to enable representation of varied experiences within study constraints. The former included individuals in the chronic stage after stroke who had attended the FES Clinic for more than six months. Carers were individuals who were active in supporting the stroke survivor in general and by accompanying them to the FES Clinic. All fell within a wider conceptualisation of ‘carer’ from Greenwood et al.[10] (p. 1331): ‘caregivers, carers, spouses or family members providing informal care to stroke survivors’. They were included to provide insights into the impacts of stroke on their lives, and any impacts of FES use. Data presented here focus on the carers only, with further results being considered for publication elsewhere.

All carers meeting this description were invited to participate through a letter from their physiotherapist at the FES clinic. They were caring for people with a range of functional abilities, increasing the range of likely experiences. This was ensured through a purposive sampling strategy; all stroke survivors were stratified according to their walking speed on entry to the Clinic, which was used to include carers of people with different levels of mobility. Individuals who were interested in participating returned their contact details; written consent was obtained at the interview.

Protocol

A topic guide was informed by the literature and designed in consultation with the research group. It aimed to focus on the study questions, while remaining flexible.[25] While the primary study aim was to explore experiences of FES, questions were included that related to experiences of stroke to provide contextual information:

- When did your [relationship] have his/her stroke?
- How did that affect your life?
- How did you feel about that?

Interviewees selected the interview location – all took place in their homes.

The research team included two specialist neurological physiotherapists involved in the delivery of services to participants (JS; KW), two physiotherapists working in Higher Education (CB; LS), and a research assistant. CB conducted interviews and primary data analysis; she is an experienced qualitative researcher with physiotherapy training, but did not have expert knowledge of stroke and was independent of services received by participants. This enabled her to approach the subject with an open attitude, aiming to bracket other influences – excluding them through self-reflexivity.[25] JS, KW and LS were involved in study design and review of the analysis.

Data analysis

Data analysis followed the ‘Interpretative Phenomenological Analysis’ (IPA) framework, which aims to interpret the way that individuals understand experiences as communicated in language.[24] Participant verification of interview summaries was carried out – summarising the interviews requires understanding and therefore involves an early stage of interpretation. This was checked by participants; two individuals made minor clarifications in relation to the sequencing of events, which were incorporated as notes in the transcripts before further analysis.[25] Verbatim transcripts were fully anonymised and pseudonyms used; alterations following participant verification were applied. Transcripts were read and re-read to gain understanding; text units were annotated with labels that aimed to encompass the

ideas and enable grouping of text units with similar meanings. These groups, or themes, were defined, ensuring that the definition encompassed all text units. Each was assigned a code for data management purposes. Code development was reviewed by the research team after four transcripts, ensuring that definitions and theme organisation were appropriate. Once all transcripts had been analysed, a research assistant reviewed all themes and contributing text units for congruence; any disagreement was resolved through discussion and modifications were applied to all transcripts.[25] Analysis focused on interpretation of the meanings communicated during interviews, categorisation of experiences, and discussion of their implications, rather than on theory development.

Results

Eight carers had participated in the FES Clinic; all but one consented to participate (88% response rate, $n=7$). Two additional carers participated unexpectedly, when they wished to stay in the room and participated in the interview at the request of the stroke survivor. While the researcher wished to adhere to a specific recruitment protocol, she did not wish to overrule the wishes of both individuals, or to disregard any contributions from the carers where they expected their views to be represented. As a result, these carers were asked whether they would like their responses to be analysed and both provided consent. Therefore, nine carers participated. One of the carers who originally consented to participate requested a joint interview. This meant that three interviews were joint with the stroke survivor, and six were individual. All carers were white British (categorised by the interviewer), and were married to the stroke survivor. Table 1 summarises participant characteristics and those of the person they are caring for, to inform the reader about potential transferability, while protecting

participant identities. Interviews varied in length from 23 to 68 minutes (mean 43 minutes; median 39 minutes).

[Insert Table 1 around here]

An overarching theme emerged, and has been named: ‘lives turned upside-down’.

This was a participant’s description that reflected other accounts of the global experiences of stroke from a carer’s perspective. Contributing sub-themes are described: changes in domestic and caring workloads, increased cognitive and emotional impacts, reduced participation in life, and changed expectations of life.

These sub-themes are likely to overlap and interact. Rather than a chronological account, they indicate areas of stroke impact during the period since stroke. Not all of the impacts had endured until the time of interview, but were important enough to be recounted in response to a general question about the effects of stroke on their lives.

Changes in domestic and caring workload

The word ‘workload’ has been used according to its dictionary definition of an amount of work carried out within a specified timeframe.[26] Workload was described as having increased by several carers once partners returned home, alongside changes in role. These were partly due to their partner’s reduced abilities in self-care and domestic activities. Daniel explained: ‘We basically feel I’m working for two people, you know, I do Karen’s work, washing – although Karen does the ironing and does the dishes. I do the garden... and the house, and keep an eye on Karen’.

One participant described increased responsibility and workload in caring for children; Shona made several comments about this: ‘with two children to look after at

the same time its quite mind boggling [astounding]... well, then they were [young] and they need your attention all the time. So you've got two children running around - maybe near a road - and you've got one adult... I'm more required, because they look to me constantly'.

Changes to workload were also related to caring tasks. Descriptions suggested that some of these tasks were not longer required after a period of time; however, while they were required they had impacts on health for more than one carer in the study. Alison described how tiring it was: 'When my husband first came out of hospital I was actually getting up about five times a night to turn him, and stretching his legs... so it was exhausting'. Moira found that task exacerbated her own chronic condition: 'For somebody of my age it was hard work... and with arthritis, I found it difficult. My arms are not very good and I couldn't wheel the wheelchair...'.

While physical workload increased, there was also evidence of emotional and cognitive impacts on the carer.

Emotional and cognitive impacts

Carers often emphasised emotional and behavioural changes in their partners, which impacted on their own emotional wellbeing. Fiona explained: 'And then in the beginning it was worse because you know I was over-sensitive to reactions from [Donald] - but he did become very, very aggressive'. More information did seem to help Moira to understand the emotional changes: 'They explained to me that the damage to the brain, the effects of the stroke, it was making him do these things, and he was so nasty he had me in tears every day. He was very, very nasty, but once again the doctor took me into his office, he says it's not a personal thing, he doesn't know he's doing it... he didn't realise'.

Alison felt that guidance would have helped her in the situation: 'They think about the physical, but they don't touch on the emotional... and if they explained to carers more, then you know what to expect and you handle it...'.

As well as the effort of coping with behaviour changes in their partners, carers also experienced stress, anxiety, depression and loneliness. Daniel described a specific moment where he felt overwhelmed: 'I just lived from day to day, you know... I had a panic attack once in the supermarket where I just abandoned my trolley, got out of the shop and drove away'. Shona talked about the ongoing effects on her psychological wellbeing: 'I'm on medication too now... it affects everybody, you know, and you start going into depression and that affects families big-time'. Fiona described feeling like a prisoner in her own home, and explained: 'I'd have been going out a bit more with my friends [before the stroke]... it's as though we've dug a wee [small] channel for ourselves...'.

Increased effort also resulted for carers in relation to forward planning; this was required for two people, as they needed to supervise their partner and remain aware of their needs. Daniel stated: 'You just feel that you're thinking for two people, you're thinking for the person who had the stroke and you're thinking for yourself'. Alison also reflected on the implications of this: 'You are the one who's got to organise everything. You can't walk hand-in-hand down the road to the nearest pub... you've got to think about what's suitable for parking, and can my husband get there...'.

As can be imagined, the increased workload and need for supervision had effects on carers' participation in life.

Reduced participation in life

Impacts on participation spanned several domains; social participation suffered for most interviewees. Lisa explained: 'It completely altered our lives, we used to be quite active. My husband liked bowling, dancing. I liked walking, dancing, but of course that all had to stop when this happened'. Moira explained why the reduced social activity had continued despite her husband's improved function: 'I couldn't go out and socialise with friends and all the rest of it, because I could not leave him. And then by the time you got it to this stage you've lost all your friends'. Alison felt that more could be done to enable carers to have more time for themselves, while giving their partner some different company: 'I just think it would be nice if there were more clubs where people could go to... somewhere, you know, with male company. It would be nice for me as well to go off, you know, without having to drag him with me'.

Several carers also experienced changes in their occupational participation due to their partner's stroke, Daniel included: 'But I retired there and then, so I didn't get myself up to retirement age, but I left work... I still miss it. I felt I hadn't finished what I wanted to complete before I left'.

Carers described the responses to all these changes in their lives.

Changed expectations of life

Several carers described a transition in their thinking, a change in their expectations of life. Some disliked the prospect of continuing to carry out specific activities, as Aaron commented: 'Now I do the majority of meal preparation... Now that's a total change to me. I'm not saying I prefer it that way, I liked it before, it suited me fine'. Anne felt that the focus of her life had transferred completely to her husband: 'My life has completely changed, hasn't it? I never have any life. It revolves around Euan'. Often

comments conveyed a great sense of loss in relation to hopes, plans and aspirations for the future. Daniel explained: 'Our lives changed 100 per cent. I've had to adapt to it, but it's not what I envisaged my retirement being'. Marie also felt that she had lost her image of the future: 'My husband had taken early retirement... we had plans that we wanted to do, and of course they were just blown out'. Shona had changed her goals in life in response to the demands of life after stroke: 'My daily aim is not to have fluctuations one side or the other, just to keep it level... I don't aim for other things that I might have done in the past because I just can't do it'.

The changes in carers' lives are described as overwhelming and are aptly encompassed in the overarching theme of 'lives turned upside-down'. The implications of carers' descriptions, reactions and needs are now discussed.

Discussion

Summary of main findings and analysis of their credibility

Participants in this study reflected on their experiences of a stroke that had occurred between two and seven years previously. These impacts were described in vivid terms that can inform people who are seeking insight into carers' experiences of stroke.

Participants found it very difficult to understand and accept many changes in their lives, including increased caring and domestic workloads, greater cognitive and emotional demands, and reduced participation in many domains of life due to the need to supervise their partners. Emotional and cognitive changes were particularly hard to understand, and more than one participant would have valued greater information and support. Descriptions reflected perceptions of loss and adaptation to different expectations of life.

When comparing these findings with previous research, it is important to remember that carers were recruited as partners of people who were attending a FES Clinic; therefore, their partners were capable of some degree of mobility, although purposive sampling ensured that the level of mobility varied. It is important to consider the high variability in the time since the stroke occurred, which is likely to have affected experiences and views. Both factors should be noted when readers analyse the potential transferability of the findings to their own contexts.

Transferability is also enhanced through strategies to improve rigour of data collection analysis; one such method is to continue data collection and analysis until no new themes emerge.[25] The study had a one-year limit, which made it more difficult to conduct iterative data collection and analysis until a point where data saturation could be determined. However, the data are relatively extensive in the context of qualitative research.[27] Participant numbers ranging from five to 22 were predominant in a recent qualitative systematic review focusing on carer experiences of stroke.[12] The reader is also provided with information about participants to enable judgments about the relevance of insights to their clinical context. The analysis process was conducted in a rigorous manner, incorporating participant verification, research reflexivity, and checking of analysis by a second team member.

Relationships between study findings and existing literature

It is most useful to compare the study findings with those of other qualitative research, where many similarities were observed. Participants in the current study expressed difficulty in understanding and accepting the changes in their lives, which has been found in several different studies.[13,14,15] Temporary and permanent increases in

the number of roles and amount of work taken on by the carers in the current study have been described by others; similar linkages were made between personal circumstances and impacts of increased caring and domestic workloads.[14,18,19,20] One participant talked about the difficulties in raising a family while caring for a stroke survivor, and others explained the physical barriers experienced from personal health conditions. These issues have been identified in other qualitative studies, which focuses attention on the context-specific and individual impacts of caring.[14,17] Greenwood and colleagues[10] have commented on the need to explore differences in carer experience, and the impact of life stage may be an important avenue for further research.

Increased workload was not just described in relation to tasks. Participants in the current study described greater cognitive and emotional demands on them that required effort. These related to greater effort required of them in thinking and planning for more than one person, and in managing their own emotions. It was noticeable that carers particularly highlighted their negative experiences of behavioural and communication impairments in their partners. Previous qualitative studies have also found that emotional and behaviour changes in the stroke survivor particularly affected the carer's well-being.[17,28] Greenwood and colleagues[10] discussed the possibility that focusing on physical disability may lead to neglect of behavioural and emotional changes. This might lead to greater support for people with physical disabilities, while other distressing changes may be allocated less assistance. The need for more information was expressed by one participant in the current study, specifically relating to behavioural changes, while another participant described the value of information on this topic. More information and training is frequently

described as a need in qualitative studies - in relation to understanding of stroke, its long-term impacts, and strategies for caring effectively.[13,14,20,21,22]

A further area of similarity between the findings of the current and previous studies related to reduced participation in life, including fewer occupational and social opportunities for interaction. Denman described the increased workload of caring as leading to restricted opportunities for social contact;[20] in different studies this has been related to the need for constant supervision of the stroke survivor, impacts of giving up paid employment, and changes in family and social relationships.[16,20,28,29] One participant in the current study explained that while at the time of the interview she would have been more able to leave her partner unsupervised, her opportunities were restricted because she had lost so much of her social network over the years. White and colleagues[3] suggest that interventions should focus on helping carers to develop strategies for managing such difficulties, increasing their perceptions of mastery over the situation.

A further theme that emerged in the current study revolved around loss and altered expectations of life. This is less frequently highlighted in previous research and seemed to be related to global changes, rather than specific increases in caring activities. It may have reflected a cumulative effect of increased roles and responsibilities, alongside a reduction in the scope of social and occupational opportunities. Smith and colleagues also found that carers reduced their planning for the future and took a day at a time, but this at times meant that 'the future looked bleak and unpromising' (p.241).[17] In a study by Dowswell and colleagues, on carer

described the loss of all their plans, and another stated that life had come to a standstill.[30] The impact of adjusting hopes and dreams for the future may be severe in relation to self-identity and self-esteem,[31] and should be further explored.

One theme area that has been found in the literature relates to positive experiences of caring,[16] although this does not emerge in many studies. In the current study comments were made in relation to the stroke survivors' survival and progress, but carers did not volunteer reflections on positive experiences perceived as resulting from the stroke, such as improved relationships with their partner or changes in their attitudes to life. According to a recent longitudinal qualitative study,[15] the latter can be conceptualised as 'absolute positives', while reflections on improvements may be defined as 'relative positives'. If questions had been included that explored positive changes, participants might have expanded on this issue. Instead, a general question regarding effects of stroke on carers' lives elicited predominantly negative aspects of experiencing stroke and its aftermath.

Clinical implications:

It is important to remember the contribution of carers, both to the quality of life of stroke survivors, but also to the health system. Without their support, many more people would require greater levels of input from health and social services.[6]

Alongside more altruistic goals, this should provide a rationale for providing sufficient support to carers, enabling them to live sustainably. When applying the results of this study, it is important to remember the relatively specific context and small number of participants. However, they support previous studies in suggesting

that information is valuable at different stages after stroke, when assimilating the implications of stroke and understanding changes in the stroke survivor. They also concur with other research in suggesting that practical support would be valuable to carers in at different stages after stroke, to reduce the physical and caring workload, and possibly increase opportunities for engagement with other people. A more novel finding relates to the process of changing expectations of life. This is not referred to specifically in the literature, however, some of the suggestions for support may help to address it. As well as practical support, several studies advocate provision of emotional support during the process of adapting to changing roles, including counselling and empathy.[20,22] Empowerment by health professionals is also suggested, which may be required to help individuals who have learned to put the needs of others above their own.[13] Further research is required in relation to the issue of changed expectations of life, and possibilities of providing support.

Conclusion

This study analysed qualitative interview data relating to the experiences of a specific group of carers' after stroke. Reactions to changes after stroke were described in the overarching theme: 'lives turned upside-down'. Carers described substantial impacts on their physical, emotional and cognitive workloads, as well as reduced participation in life. Support in understanding the long-term implications and cognitive and emotional changes in their partners may have helped them to adjust. Further opportunities could be provided to help reduce feelings of social isolation and of increased workload. Further research is needed to explore the impacts of changing expectations of life, and the potential for easing this process.

Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Table 1: Participant and interview characteristics

Pseudonyms	Characteristics of interviewee		Key information about the stroke survivor	
	Male/ Female	Age Range	Left/Right hemiplegia	Years since stroke
Carer interviews & data relating to the person they care for				
Aaron	Male	55-59	Right	5
Daniel	Male	60-64	Right	5
Lisa	Female	65-69	Right	3
Alison	Female	50-54	Right	6
Marie	Female	65-69	Right	7
Shona	Female	40-44	Right	2
Joint patient and carer interviews				
Jack (patient) & Moira (carer*)	Male & female	70-74 & 70-74	Left	6
Donald (patient) & Fiona (carer)	Male & female	70-74 & 70-74	Left	3
Euan (patient) & Anne (carer)	Male & female	60-64 & 60-64	Right	4

* Unexpected carer participation, post-hoc consent;

N.B. Communication ability varied but was not assessed clinically.

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